

Declaration of consent for the use of health-related data and samples for research purposes and for a blood sample

Patient's surname and name

Date of birth

1) I herewith agree

that my health-related data and samples collected during health care (ambulant or as an inpatient) will be available for research purposes

YES NO

2) I herewith agree

- that a blood sample (maximum 20 millilitres, which is equivalent to two sample tubes) may be taken from me for research purposes
- that if required the following additional details may be collected together with the blood sample: height / weight / ethnic group (e.g. Caucasian)
- that my biological material and health-related data can be used according to part 1)

YES NO

I understand

- the explanations about further use of my health-related data and samples for research purposes that are detailed in the information sheet (V3.0 August 2020).
- that my personal data are protected.
- that my data and samples may be used in national and international projects, within the public and private sectors
- that projects may include genetic analyses of my samples for research purposes.
- that I may be recontacted in case of individually significant findings, if any.
- that my decision is voluntary and has no effect on my treatment.
- that my decision is not limited in time.
- that I may withdraw my consent at any time without having to justify my decision.
- that I can read the Liquid BioBank regulations at any time on www.biobankbern.ch

Place, date

Patient's signature, if judicious

Place, date

Signature of legal representative, if required
(Name and relationship to patient)

Please consider the following contact or your physician if you have further questions or if you wish to receive a copy of this form with signature.

Directorate of Teaching and
Research

Information about the use of health-related data and samples for research purposes

Dear Patient

Our ability to diagnose and treat diseases has progressed significantly in recent decades. These progresses are the result of long-standing medical research in which doctors, scientists and patients of several generations have actively participated. An important part of this research relies on patients' health-related data from medical history, such as results of laboratory analyses, therapy information or genetic predispositions. Any biological material collected during the hospital stay and which is no longer needed for the treatment, is also extremely valuable for research. These leftover samples can be for example blood, urine or tissue samples.

This leaflet explains how patients can contribute to medical progress and provides information in terms of data protection and associated rights. Thank you for your interest and attention.

How can you contribute to research?

By signing the declaration of consent with «Yes», you are making your clinical data and leftover samples available for research purposes. Data and samples include those, which have been collected and will be collected during your hospital stay. Your consent is voluntary. It remains valid indefinitely or until withdrawn. You are entitled to withdraw your consent at any time without having to justify your decision. After withdrawal your data and samples will not be available for new projects. Your decision has no effect on your medical treatment.

How are your health-related data and samples protected?

Data are stored within the hospital and protected in accordance with the applicable legal requirements. Only authorised employees from the hospital, e.g. physicians, have access to your uncoded data and samples. Your samples are stored in biobanks which contain structured collections of samples under safety regulations (biobank regulations).

If your data and samples are used for a research project, they will be coded or anonymized. Coded means that all personal information such as your name or birth date is replaced by a code. The key showing which code belongs to which person is kept safe by a professional who is not involved in the research project. Persons who do not have the code are not able to identify you. In case of anonymization, the link between the biological material and/or associated data and the participant is definitely removed, so that no specific participant can be reidentified.

**Directorate of Teaching and
Research**

Who may use your health-related data and samples?

Data and samples may be used by authorised researchers for research projects within the hospital or in collaboration with public institutions (such as other hospitals) and private entities (such as pharmaceutical companies), in Switzerland and abroad. For research abroad, it must be ensured that at least the same data protection conditions are followed as in Switzerland. The projects may include genetic analyses for research purposes. Research projects relying on your data and samples have to be authorized by the relevant ethics committee.

Will you be informed about research results?

Research carried out with your samples and data will generally not reveal any individual information for your health. In rare cases, research results might be relevant or significant to your own health and clinical action might be possible. In these cases you might be informed.

Will there be any costs or financial benefit?

There are no additional costs generated. The law excludes commercialization of data and samples. Thus, no financial benefits will be generated for you or the hospital.

If you have any questions or would like additional information, please contact us at the address below or visit our website.

Directorate of Teaching and
Research

Consent for a blood sample for Liquid BioBank Bern

To achieve significant research results, researchers require access to large numbers of high-quality samples. This is why it is of paramount importance to Insel Gruppe that an additional blood sample can be taken from patients. You must give separate consent for this blood sample.

How will your sample be used?

The storage and passing on of your sample are governed by the same standards that apply to health-related information and medical samples. You can, in particular, refuse to give or revoke your consent at any time without giving any reason. In addition, the management and passing on of samples are defined in regulations authorised by the cantonal ethics commission.

Why is an additional blood sample required?

Compared to investigations carried out for your treatment, research has different requirements for the quality of samples. It is of particular importance that all samples used in a study are processed in the same manner. How a blood sample is taken, transported and stored affects the quality of the sample. The additional blood sample means that these processes can be standardised and documented. Quality assurance and storage are guaranteed at Liquid BioBank Bern. This means that Liquid BioBank Bern can provide various research projects with samples of uniform and consistent quality.

Why is additional information (height/weight/ethnic group) required?

Your blood sample is extremely valuable for research. In addition to existing health-related data, this additional information helps to categorise the samples. This means that your sample can be made available to those research projects that will derive the greatest benefit from it.

When will the blood sample be taken?

The blood sample will be taken during your stay in hospital. You will not need to attend a specific appointment for the BioBank blood sample.

What is a biobank?

A biobank is a collection of samples, amassed for studies or general research purposes. Data on the sample itself and on the donor are recorded for each stored sample.

What is the purpose of Liquid BioBank Bern?

Over recent years, samples have predominantly been collected specifically for individual studies. This has meant that valuable material from trial subjects was only available to a limited circle of researchers. The aim of Liquid BioBank Bern is to establish a collection of samples that can be made available to various research projects. This will increase the benefit of individual samples for research and reduce time and costs for medical research.

Where can you find further information about Liquid BioBank Bern?

Liquid BioBank Bern (LBB) belongs to Insel Gruppe. LBB was established to provide effective facilitation of biomedical research in particular and to support it through the provision of patient samples of outstanding quality in an international comparison. Its aim is to improve prediction, prevention, diagnosis and therapy in human medicine. In addition, the collected samples and data can be used to investigate fundamental mechanisms required for the understanding of diseases.

To find out more about Liquid BioBank Bern, please visit our website: www.biobankbern.ch.